Talking to Kids Throughout Cancer and Accessing Support for the Whole Family

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Presented by:

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Aimee Sax:

Thank you so much for joining us today. We are so excited to have everybody here for our Sharsheret webinar, Talking to Kids Throughout Cancer and Accessing Support for the Whole Family presented in partnership with Pickles Group and Imerman Angels. I'm Aimee Sax, California support program manager at Sharsheret. For those of you who don't know about Sharsheret, we help women and families facing breast and ovarian cancer as well as those who are at elevated genetic risk. Through free, confidential, and personalized support and resources. It's important to note today, since our partners today serve all cancers that someone with a different type of cancer calls us, we won't turn you away. Just know that some of our resources aren't going to be the best fit, but we will always provide some support through our team of social workers and refer you in the right direction for anything that isn't a good fit for you.

In addition to our virtual services, that can be found on our website or by emailing us, you can also access prior webinars and a range of cancer-related topics, as well access our calendar of upcoming virtual events and programs through our website. The link for that will be in the chat. Before we begin, just a few housekeeping items. Today's webinar is being recorded and will be posted on Sharsheret's website along with a transcript. Participants' faces and names will not be in the recording as long as you remain muted. If you would like to remain private, you can turn off your video and rename yourself, or you can call into the webinar, instructions for that are in the chat box now. You may have also noticed that you were all muted upon entry, so please keep yourself on mute throughout the call. If you have questions for our presenters, you can put them in the chat box openly to everyone, or click on Sharsheret in the chat box to submit a private question and I'll ask them throughout the program.

We also received a couple questions in advance, so we will do our best to get to as many questions as we can. And we will send up a follow-up email from today's webinar with the recording and any other resources and links and contact information in the next week or so. As we move into the webinar itself, I also want to remind you that Sharsheret is national not-for-profit cancer support and education organization, and does not provide any medical advice. If you have any questions that are specific to your medical care, we advise you to speak with your medical provider, always seek the advice of your physician or qualified health provider with any questions that you may have regarding a medical condition. We're so excited to bring you today's webinar. We want to thank our generous sponsors, GSK, Daiichi Sankyo, and the Cooperative Agreement DP 19-1906 from the Centers for Disease Control and Prevention, whose support allows us to create and provide important educational programming like today's webinar.

Kelsey Mora is a certified child life specialist and licensed clinical professional counselor who specializes in supporting children and families impacted by medical illness, injury and grief. She has extensive experience providing individual and group services to children who have a parent with cancer. Kelsey, both guides parents and caregivers on how to best support their children and teens, as well as create unique opportunities to help youth make connections, and increase coping and communication throughout a cancer experience. Kelsey works in private practice, is the author of The Dot Method, an interactive tool to teach kids about cancer. And is the chief clinical officer at Pickles Group, a nonprofit that provides free support and resources to children and teens impacted by their parents' cancer. Kelsey, welcome and thank you so much for being here today. We're so lucky to have you.

Kelsey Mora:

Hi everyone. Thank you so much for having me. I'm just going to quickly share my screen so you all can follow along with the presentation. All right, so I'm Kelsey Mora, I'm the chief clinical officer for Pickles Group, and I'm going to spend some time talking about how to talk to kids throughout cancer. Just a recap of our agenda. So I'm going to share a little bit about developmental responses for different age groups. I'm going to talk about infancy through adolescence. We're also going to take a closer look at three tips that Pickles Group has developed in talking to kids about cancer. And when we talk about those three tips, I really want you to get in the mindset of applying those tips to any difficult conversation throughout a cancer diagnosis and treatment experience. Because while often people think of that initial diagnosis conversation, these tips can really be applied to any hard conversation, whether it be a surgery, a change in medication, a recurrence or another difficult conversation that you're having related to a cancer experience.

And those tips are pulled from our free family cancer support kit, which is something that anyone can request for free on our website whether you are an individual or a healthcare provider. And then I'm going to turn it over to my amazing partners here, both at Imerman Angels and Sharsheret to discuss how collectively you can access support for your whole family. So because of our peer-to-peer support services, together, we really feel like we can make sure that everyone in the family has access to support. Specifically for Pickles group, we're going to talk about the kids in the family. In order to build peer-to-peer support for kids, we recognize that, that really has to start with the parents and caregivers in their life in terms of how they're talking to kids about cancer. So I'll start with the developmental responses and specifically infancy and toddlers. So we'll start at the very beginning.

This is an age group that people often assume have limited understanding and comprehension. They might say things like, "They'll never understand," "They'll never remember." There is some truth to that of course, just with their development. That being said, it doesn't mean that it's not impacting them. So little ones will sense changes in their environment. They'll be aware of how others are acting, maybe disruption, maybe their primary caregiver is suddenly in the hospital and there's a bunch of extended family members showing up to the house. Or maybe there's heightened emotions around them, maybe their caregiving or their feeding schedule has changed. In the instance of breast cancer, we often see a lot of parents who are unable to hold their infants and toddlers following a big surgery or things like that. So that can really affect infants and toddlers. And they may have some thinking around, "Did I cause this?" "Why is my parent not holding me?"

So even though they're so little, we do want to explain in really simple terms why that's happening. In terms of preschoolers, so this is that age group that's starting to develop more language. So they do understand a little bit more, but they're often going to relate it to what's familiar to them. So if we think about preschoolers who are maybe starting to go to school, interact in a classroom or child care setting, they're often talking a lot about germs and covering their mouth and runny noses. So they may think that every sickness is the same. And so when we're talking about cancer with preschoolers, it is important to talk about cancer as something different. That it's a problem with the cells, it's not contagious, it can't be shared, but also the recovery or the treatment looks a lot different than a cold or a flu.

It's going to be much longer. A person may look a different kind of sick. So helping preschoolers really distinguish the difference between cancer and maybe what they're used to when they hear words like sick or medicine or things like that. They also have a lot of magical thinking. So this is the age group that is thinking a lot, trying to make sense of the world around them. So they might think things that are really far from the truth, maybe even kind of fantasy or made up. So having parents and grownups who can explain things to them in a way that makes sense to them can be really helpful for them to have honest information, and not feel like they need to try to make sense of things on their own. And then we have the elementary age range. So these are kids who are going to school, they're interacting with peers more regularly, and they also can understand more, but this is when they might have misinformation.

Kelsey Mora:

They might not feel like they can ask their questions. So they might ask questions to maybe a friend or maybe someone who's not familiar with the situation. Or in a family that has access to internet and technology, it might be a kiddo who's searching things on their own. So it's really important to have those conversations together and to monitor where they're getting their information, and to also show them that it's an okay thing to talk about in the family. So this is really important for those kids who are leaving the house and interacting with others. Because if their trusted adults aren't the ones telling them, they might find out from someone else who comments about their parents' appearance or their parents not being present or things like that. And then lastly, adolescents. So this age group is also a little bit misunderstood because we assume they understand, but they are still young and they may have never experienced anything like this before.

So they might be thinking about really big picture. Often they're thinking, "How is this going to affect me?" That's not selfish. It's very normal at this age group to be thinking about, "How is this going to affect me?" "How is this going to affect my schooling, my peers, my activities?" They might be struggling with roles. Maybe they're the oldest of a large family and they needed help with caregiving or help with other things at home. And that can feel confusing because they also have things that are important, independent to them. So having those open conversations with teenagers about how this is affecting them and how we can work together to make it work for everybody can be really important. Because if not, they might express their feelings. Maybe they're going to feel kind of angry or maybe they're not going to be as helpful and it may seem like they don't care or they're not understanding. But it may mean that they actually have feelings that need to be expressed and discussed so that they can better understand and work together with the family.

So now I'm going to pivot away from those age ranges and really talk about these three tips that can be applied to every age group and every difficult conversation. And as I said before, these three guiding tips come from the image that you see on the screen. This is our family cancer support kit, and that's a resource that's free through Pickles Group and it's available both in English and Spanish. So the three tips that we focus on are sharing information, sharing expectations, and sharing feelings. And I'm going to break each of those down a bit further. So I'll start with sharing information. So often as a parent or caregiver, you might be thinking, "What do I tell my kids?" Or, "Where do I begin?" So it can be really helpful to think about how to set up conversations. And sometimes parents are worried, "If I set up a big sit-down conversation, is it going to feel more intense than it is?" And truthfully, it is intense.

So it's okay for it to feel like a different conversation. It's different than a regular daily conversation, but also it creates some predictability and some structure around how these conversations are held. So we do want to try to aim for a time when kids are maybe well-rested or well-fed, maybe not rushing between things, maybe not right before bed. So really thinking about where this should take place, when, who could be there. So if you're the primary adult that's going to be having this conversation, is there someone who can be with you? Is there a co-parent? Is there a partner? Is there a relative, a friend? So that you have an adult companion to help you with those conversations. And then it's really important to give kids what I call a warning or a heads-up. So saying something like, "I have something important to talk to you about," or serious to talk to you about. And that can just help kids tune in a little bit differently that the conversation that's coming next is different than a regular conversation.

We do want to think about not only who the kid is today, but who they'll grow into. So even if kids are little, but we know that this cancer experience is going to span their development, we want them to get older and be able to say, "I'm so glad I knew and understood," rather than, "I wished I had known." So we just start a conversation and then we can build on it. It's not a one and done conversation. These conversations evolve and when you establish how information is delivered and create that openness and honesty, it makes for really supportive, subsequent conversations. So it can be helpful to use real words. So what do I mean by that? I talked a little bit about the difference between sickness and cancer. Not every family is comfortable using the word cancer, and that's okay. Sometimes my response to that is the risk is that they may hear cancer from someone else and that may disrupt trust.

Like, "Why didn't I hear that word from my parents?" But it is okay to talk about cancer as a problem with the cells and then communicate with other adults in the family how you're talking about it with your kids. Keeping in mind that, "I don't know" is a real answer too. So if kids are asking really hard questions that you don't know the answer to or you're not ready to answer, you can always say, "That's a great question, I don't know the answer to that, but let's find out together. Or as soon as I do, I'll come back and talk about it." And then of course, following their lead. So when you're trying to think, "How much do I tell them?" So we've talked about how to start a conversation, but how much do I need to tell them? Really asking yourself, "What do my kids need to know right now?"

"What are they going to see? What are they going to observe? What are they going to experience?" So if you're at an earlier stage of a diagnosis, it might be a hospitalization. They need to know, "Where I am and why I'm gone?" Or coming home following a surgery, what does that look like? How's that going to affect them? Well, a parent can't drive, a parent can't hold them. We're going to have extra caregiving help. Those are going to be changes that they're going to see and experience and be curious about. So when we talk about what they need to know, that can lead to what they want to know. So they may ask more questions, they may not. I recently did a project on different responses that kids may have following a difficult conversation. And it's really important that every reaction is usually normal.

So if you have a kid who gets really quiet, that's okay. If you have a kid who wants to go run and play, that's okay. If you have a kid who has a lot of questions, that's also okay. I really believe that when kids have those responses, they're just showing you what they need in that moment. It might be space, it might be curiosity, it might be a break, and all of that is okay. It doesn't mean that your conversation went poorly, it just means that they're showing you what they need. And they will kind of self dose how much they can handle at any given time. So they'll show you, "I think I've had enough for now" or, "I need a lot more." And really there's no specific script. So if you're feeling nervous about any conversation, just remembering that having the conversation in the first place is really just about opening the lines of communication and building trust with kids, which ultimately reduces their fear.

So the next tip is sharing expectations. So this is when we might move a little bit past some of those acute conversations, and think about when do we have those conversations and when are we talking to kids? So a lot of times parents might fear, "If we're talking about cancer, will it be all we're talking about?" And in my experience, I often find that when we're talking about the hard thing, we are talking about it less. Because kids start to learn and trust that we'll talk about it when we need to, when there's a change or an update or when the child has questions. So really focusing on any changes. When there's maybe a change or an update, talking to kids about what's going to be different. There will be a lot of things that change, but there's also things that can be the same.

So talking to kids about what's going to be different and what's going to be the same. "You're still going to go to school, but grandma or bubby is going to take you." So helping kids understand who's going to be there for them. Also talking to them about the unexpected, and we can't predict everything, but when get used to honest information, then when something unexpected happens, it's not as hard to talk about it. Because we can say, "Oh, remember how dad has a problem with their cells? They're in the hospital right now because they had a fever, and the doctors have to keep extra care on them and then they'll be home soon." So we are not starting from the beginning. We can build on what we've already discussed. Obviously navigating cancer with kids, there's a lot that can feel out of everyone's control and that includes kids.

Kelsey Mora:

And kids really benefit from feeling a sense of control when there's so much change in their environment. So one really simple way to do this can be to provide kids with choices. It can be really simple choices that have nothing to do with the cancer. It might just be, "Do you want the Red Bull or the Green Bull?" It just helps them feel like they have control over something. And we want to make sure that the choices you're giving them are favorable choices. Like you're okay with either thing that they pick. If it's bedtime, maybe it's, "Do you want two books or three books?" Maybe it's not two books or 10 books if you're not okay with 10 books at that time. But really giving them choices that you're okay with them picking. And that creates some limits and boundaries, which helps with structure.

You may also be providing choices about how involved the child wants to be. Can they come visit and see the clinic? Can they make a picture for your hospital room? Can they help pack your bag with you? Do they want to be involved in any caregiving? Some kids feel really empowered and honored when they can get their parent water or help with something. Sometimes that can be overwhelming to do those things. So really providing different options for how involved kids want to be. And also for older kids, choices can still be really helpful. They might be... You know homework's not a choice. "Do you want to do it now or in an hour?" The homework is a thing that still has to happen, but can we choose when we do it or how we do it? So usually any situation has some level of choice and trying to tease out what that is can really help kids feel empowered, and that they have some agency and autonomy to make decisions for themselves.

And then this is a tricky one, but I'm going to explain it further. So keeping things consistent. Well, we know when navigating cancer, there's not a lot that feels consistent, not a lot that feels normal. And that's why it's so important to find ways to build back in that structure, that routine, that predictability. Even rules, sometimes when navigating a hard thing like cancer, it might feel really natural to want to give in or be more flexible, and there might be a time and place for that. But kids really thrive when they know what's expected of them and they have structure. So we know that their school work or their studies or their activities are the things that give them some purpose and some stability. So really thinking about what matters to them and really prioritizing these things. Also as a parent, giving you the opportunity to parent your child.

So I've worked with families where kids are worried about bothering their parent with homework or friends. They don't want to bother them because they have so much going on with the cancer. And often parents want nothing more than to feel like that normal parent. So being able to have those normal connection moments both for kids and for parents can be really, really healing and supportive for everyone.

So the last tip is about sharing feelings. And this is really about often when we can't control a situation, we can't control how supported kids feel. And it's not uncommon to feel like you need to be strong for your kids. I put that in quotations, because I think we really need to ask ourselves, "What does being strong really mean?" And it can be really helpful for kids to know that all feelings are okay and to see that in their trusted adults.

So being strong might actually be modeling for your children different ways to feel, and acknowledging that the range of those feelings is okay. Even playing and being joyful and having laughter and fun moments can be really important. And that way kids know that it's okay to still have fun. It's okay to play. It's okay to feel natural and normal and have moments where, "I'm feeling kind of sad and disappointed and I wish that you could play more with me," or things like that. So modeling that for children can look like increasing your own communication and saying things like, "I feel sad because I need to go to the hospital today and I wish I could be at your performance." Or, "I feel disappointed because dad's not feeling well and I'm going to make him a card" or, "I'm going to take a deep breath" or, "I'm going to find something that we can all do together."

So really working with kids to practice coping skills. There might not always be solutions, but there will always be a support. And kids often need support over solutions. So that can look like really embracing those feelings together, that all feelings are okay and we need to find safe, healthy outlets for those feelings. So remembering really those body basics, like making sure basic needs are being met, hydration, sleep, nutrition, those can really help kids cope well when their baseline is kind of more supported. But then also things like breathing that can really help just regulate the nervous system for you, for your kids. Different outlets, not every kid needs calm outlets. Some kids need to run in place or do jumping jacks or squeeze things or throw things that are safe to throw. Sometimes kids do need music or they do need stretching. So really normalizing the different types of outlets, creative outlets. Maybe you have a kiddo who benefits from art or writing, or music.

But really acknowledging that everyone copes different. And the important thing is that you're making time and space for that coping. And those are transferable skills to everyday life. So regardless of the fact that you're focusing on it as a result of this difficult time with cancer, those are skills that can be really helpful to kids throughout their lifespan. And so they're good things to just practice regularly and to help bring the family together through a hard time.

So I'm going to talk a little bit more about Pickles Group as an organization. That was kind of a brief overview of how to talk to kids about cancer and different parts of cancer and our three tips. But again, the ways that we support families, I'm going to talk about a little more detail in case you're wanting more. So our mission is free peer-to-peer support and resources for kids and teens impacted by their parents or guardian's cancer. So when we talk about accessing support for the whole family, we are really bringing kids together and so youth peer-to-peer support. We have a research article from 2017 by Binay Shah and colleagues that really speaks to what three things kids need to thrive through a parent's cancer. So those three things are listed on the screen here. The first is honest and age-appropriate information. The second is coping skills, and the last one is connection to peers.

So we really recognize and value all of our programming is rooted in these three things. We believe that when kids have an understanding of what's going on, they have coping skills and they feel connected that they can have an easier time navigating their parents' cancer. So how do we do that? So I talked about our free family support kit. Usually when families first engage with Pickles Group as an organization, they're receiving or requesting our support kit. We have distributed, I think almost 30,000 of those across the country in different healthcare centers. So if you're getting treatment at an infusion center or a clinic, we want hospitals to be handing that support kit to you when you're asking, "How do I talk to my kids about cancer?" But if we're not there yet, we're only a 3-year-old organization, you can request one on your own.

You can go on our website, request that, we'll send it digitally or in print. And it has more information about the three tips I talked about today as well as those developmental responses, a family-friendly activity, common questions that kids ask about cancer, as well as some additional supportive information in there. From there, we do a lot of webinars similar to this. We have a How to Talk to Kids About Cancer webinar. We have a clinician webinar for healthcare workers. We also have some on-demand content. So we have a four-minute recap of the three tips on our YouTube channel, so different ways to get that information as a parent. Once parents feel more confident having those age-appropriate conversations with their kids, we engage our kids. So we have a Connect Over Cancer program and I realize it says fall on there. That meant to say winter.

We are currently enrolling for our winter cohort. Registration actually closes this Friday. So if you have first through 12th graders in your life who could benefit from this program, it's completely free. It's five weeks, it's virtual, it's national. I designed the curriculum, it's a social-emotional curriculum, but then we have trained and skilled volunteers who deliver that. And your kids will be with same-aged peers across the country who can connect with a parent living with cancer. And then after that Connect Over Cancer program, we also have ongoing ways to stay involved. We have a monthly program that's in pilot mode right now called Pickles Jars, so it gives kids more frequent long-term points to stay connected. We're really about closed groups, so the same group of kids is seeing each other each time to build deeper relationships. And then we also have some in-person programming in the Chicagoland area as well as Columbus, Ohio.

Those are quarterly events that are kind of the family outings, that are focused on fun and connection. Last but not least, I am in the works of planning our 2025 webinar series and some of our other on-demand content. But I can tell you for sure that on January 24th at 1:00 PM Central, we are doing a collaborative webinar and panel with other organizations who support children of parents with cancer. So that's Wonders & Worries, Bright Spot Network and Kesem. I'm going to be doing a similar talk today, but then we're going to have a panel where you'll hear from parents themselves who are also in nonprofit leadership roles. So that's going to be on our website very soon. We're just working on the final details and that's something that you can register for as well. So next steps, you can email us at contact@picklesgroup.org, you can visit our website, picklesgroup.org.

If you're a social media user, we are on all of the common social media channels putting out content and reminders. And for those of you who shared your contact information, we'll add you to our email list so that you're getting updates. But again, our registration for the winter cohort does close on Friday. So if you're a family who could benefit from this now, we would love to have you enroll. And you can reach out to us right away and we'll get those forms filled out so that your kids can be part of our Winter Connect over Cancer program, which starts in January. Thank you so much. I'm going to stop my screen and turn it over to Jackie with Imerman Angels.

Aimee Sax:

Actually, Kelsey, we had a couple questions for you coming through the chat, so thank you so much, let me just say first before we get to the questions. This has been so helpful. I've already heard you give a few trainings, both to the Sharsheret staff, and I've watched some of the Pickles group webinars, which I can attest to being fantastic, and I learn something new every time. It hits you different and you're really updating. So I really appreciate everything you shared. So helpful.

So the first question is about a possible reoccurrence, which I know can be a triggering topic for some. So if this feels triggering to you, feel free to close your ears for a moment. "My son is nine and a half, and I'm currently in no evidence of disease but being monitored for slightly increasing lab work. And should our family be in that position again? I feel like telling a child that it came back and chemo may happen again, would be even harder for them to understand and accept with more fear attached this time. That would be super helpful to hear about." Do you have any thoughts for somebody dealing with a reoccurrence?

Kelsey Mora:

Yeah, yeah, definitely. I mean, I think some of it... I understand that balance of integrating the gratitude around being no evidence of disease and also hopeful, fearful all at the same time, it's such a common experience that I see parents and families navigate. And I think similar to the tips we talked about today, some of it's going to depend on how the diagnosis was discussed. When it was active, a child might've been a very different age, so nine and depending on how long it's been, they might've been much younger. So really assessing what they already know and understand, really needing to build on what they understand. You might be feeling like you're having a first time conversation about cancer again if you find yourself in that position. But really being able to build on that and starting with, "I have some unfortunate news, I have some sad news."

We talked about that warning sign. "Remember how a cancer is a problem with the cells. I had all of that medicine and it really did get rid of those cells, but I had another test or I had..." You know, explaining however it was found. "And there's some cancer cells in my body again." So explaining, going backwards, whatever they understood, giving a warning, giving a really simple but honest matter of fact explanation and then talking about what they need to know right now. So again, if there's a treatment plan already or if you're waiting for more information from the doctors, but you're telling them now because they're picking up on the disruption with doctor's appointments or your mood or energy, all timing is okay for your family.

But that may dictate what's coming next, but then explaining to kids like, "Here's what we know," and also really following the doctor's leads. It's like, "We're learning from the medical team about a medication that we can take this time," or a surgery or whatever that treatment might be. So again, it's applying those three tips to different conversations.

Aimee Sax:

Love how applicable they are. It's so, so helpful. That's great. Thank you. Okay, the next question. "My son is a 28-year-old developmentally delayed individual and I'm dealing with a metastatic breast cancer diagnosis. I'm not sure how to make him understand. I also haven't told my elderly parents," so this might be a question for Jackie who's going to be talking about communicating with caregivers. And, "I'm an only child and my son is their only grandchild, so I just haven't been able to bring myself to tell them of my diagnosis." So maybe you can focus on the 28-year-old or just kind of developmentally delayed children at any age. Maybe we'll save the second half for Jackie next.

Kelsey Mora:

Yeah, yeah, I mean obviously you know your child best and neurodiversity can look so different, and neuro types, so it's really going to depend on maybe how you've adapted delivering information throughout their lifespan. I'm sure there's techniques and tips that have been learned over the years with all interactions and conversations. It may be adjusting that conversation to their developmental level. So when I was talking about different developmental stages, I was talking about neurotypical youth, so it may mean that if you have a 28-year-old who's neurodivergent and maybe identifies intellectually or cognitively at a lower level, you may be using a much simpler language. There are a lot of books available. We list many on our website. So if you go to programs and learn, I can even add this in the chat, we have a link and we don't want to have an exhaustive list, because we know it can be overwhelming for parents and caregivers.

But we do have some children's books and there is actually one that's intended for... I believe it's for autistic children, but it is for neurodivergent children. It's kind of more of a social story. So depending again on his level of cognition, you might be using books or hands-on tools. The Dot Method that I wrote is a hands-on tool, so that can be helpful if you have more of a tactile learner. So really just depends. It's a lot about adapting and modifying the information to their development.

Aimee Sax:

Great, thank you so much.

Kelsey Mora:

I'll add that our youth programming while it goes to 18, we have a disability inclusion criteria that goes up to 22. So if we have a kid who's in transitional education programs, we would include them. We just have a few extra steps that we tend to take to make sure it's the right fit for everybody.

Aimee Sax:

A good fit, absolutely. And I will, just spoiler alert, for my section at the end share that we do have as part of our Busy Box program for children. We do have a special book that we will send to anybody who has a child with special needs, which is maybe the same book you guys refer to. So definitely whoever put this in the chat, please get in touch with us. We would love to send you this book because it might be a good fit. And then this is a little specific, but because it might be helpful for more people who hopefully are signing up by Friday for the next cohort, somebody who did register for the five-week program asked, "Will us parents receive a more in-depth outline of the course? Thank you so much."

Kelsey Mora:

Yes. So if you are enrolled in the course, you will get a lot of information both emailed to you and mailed to you. So you'll receive an actual packet in the mail. It's a bound workbook that has all of the activities as well as question prompts for parents, the themes, as well as a lot of detailed emails from Cam who's our program director. So we're in the crunch mode of trying to get all of our last families and youth enrolled. The number is ticking up quite rapidly. So once we have those groups formed, there will be a lot of information that's coming out, including... There's also a optional parent virtual onboarding meeting as well.

Aimee Sax:

Perfect. So hopefully the number will keep ticking up after today's webinar. Thank you so much, Kelsey. Like I said, it's been so, so helpful having you present. Now I'd like to welcome Jackie Herigodt from Imerman Angels to share a bit about how Imerman Angels can help support you and your loved ones. Jackie has been with Imerman Angels since 2012. She's been a caregiver to several loved ones with cancer, including her sister who's currently fighting stage four breast cancer and is a Lynch syndrome carrier. Jackie has also dealt with a personal skin cancer diagnosis as well, losing many family members to cancer and caring for them while battling cancer herself has fueled her passion for the Imerman Angels mission. As director of partnerships and engagement, she oversees the Mentor Angel training process, the community events, and the organization's outreach and engagement efforts. Jackie was responsible for the creation of the outreach initiative at Imerman Angels.

Additionally, she established the Global Ambassador Initiative comprised of volunteers who have dedicated their time to spread awareness about the Imerman Angels mission. Her professional goals aim to continue fostering a strong and diverse cancer community, strengthening partnerships with cancer organizations, cancer centers, and hospitals to expand the reach of the Imerman Angels mission. She holds a Bachelor of Arts in psychology from Northeastern Illinois University, has worked in the fields of animal training, I want to hear more about that, customer service and education. Her diverse background has proven beneficial for her role with Imerman Angels. Jackie, thank you so much, we're so lucky to have you today.

Jackie Herigodt:

Switching over all the screens, can you hear and see everything okay?

Aimee Sax:

Yes.

Jackie Herigodt:

Okay, perfect. Thank you. Well, thanks for having me. Thank you for this invite and I appreciate everything that's already been shared. In fact, I've asked for a few of the resources myself so that way we can continue to educate our community a whole lot more. So I always like to start my presentation off with this weird slide. It is intentional, but it's always fun because people do react very differently. Sometimes they're like, "Yikes, that's the wrong slide. What is she doing over there?" But it is intentional. I show this because it's pretty simple to understand. Most people have heard from other people about a restaurant or they have decided that they wanted to attend a new restaurant, they wanted to check it out. But a lot of times people will go ahead and ask a question to someone they already know may have been there.

So they'll say simple questions like, "Well, how was the food? How was the service? Was it expensive? What did you wear? What did you order?" And maybe, "Where did you park?" And my most favorite question is, "How was the dessert?" So you see, you have questions about a restaurant. So of course if somebody gets diagnosed with cancer, they too are going to want to talk to someone who's been there. Their questions may look different of course, and obviously pertaining to this particular webinar, your focus may be like, "How do I go through this diagnosis and help support my kids?" You know, "How will I be able to go through my treatments and get them to school?" You'll have so many questions, it's like, "Will I be able to continue to work and go through cancer?" "And does anybody really understand what I'm going through?" And if you're a caregiver, you too will have questions.

"How do I help my loved one get through this experience?" And if you're a parent caregiving with this person diagnosed, you too are going to have concerns about your children's well-being and how do you all get through this experience. And if you're a previvor, somebody that has a genetic mutation, you may wonder, because you've already seen a lot of family members go through this, what does that look like for you. Should you have prophylactic procedures? Should you not? Should you talk to your kids about it? All of these questions. So I'm telling you that people are having these questions every single day. It's not just you. We know that people are feeling more isolated and alone now more than ever, and it doesn't have to be that way. You see, there's a free organization out here to support you and get you connected to someone who really understands.

This is why Imerman Angels exists. We connect one on one, a person that's already been there, done that, for all cancer fighters, survivors, previvors and caregivers. So that they don't have to go through and you don't have to go through this experience alone. We envision a world where cancer is not a solitary experience. Now why am I the one talking to you all about this and sharing the mission of Imerman Angels? Well, you see, I too have a personal experience with cancer. This is not just professional. I'll tell you that when I came to Imerman Angels, I had already lost my grandmother, my grandfather, my uncle, my aunt, and even my mom to cancer. So with me, I had so much pain, but Imerman Angels allow that to turn into power. You see, I was able to lend this experience, this empathy, all of that to someone else that was newly going through this experience as a caregiver.

I knew that I didn't have the money to fund a cure, and I knew that I didn't have the brain to find the cure. But with my experience, I was able to do something else in another way to help other people. I became what's called a Mentor Angel. A Mentor Angel is a volunteer, a cancer confidant that has already gone through these experiences. They can shed some light, some comfort, some understanding, some tips and tricks to newer people that are just coming down the road. You see, we believe that Mentor Angels too gain trauma mastery over what they have already experienced. So it's a gift for mentors as well as it is for someone just needing that extra support. So a Mentor Angel may share a tip about how did they talk to their children about cancer, how as a caregiver, did they help get their kids to school and get their loved one to their treatments, how did they continue to work.

These are all questions that come to us every single day from around the world and we get people connected to someone who's had that actual lived experience. Now, a lot of people wonder about our training of our mentors. We absolutely do train our mentors, but obviously the bulk of their training is their own experience. We can't train them on that, nor would we want to, right? But we do give them a Mentor Angel training guidebook and they go through quizzes and videos to make sure that they understand how best to be somebody that can support others going through this. And we set up clear expectations and always allow the mentors to know we're there for additional support.

Now, where's this magic happening? As I mentioned a little bit earlier, it is global. We've been doing this for over 18 years now, and we are doing this in over 120 countries. We serve all cancer types and we have over 15,000 Mentor Angels that have registered with us. And while that sounds like a lot, everybody has unique experiences. So, we're always looking for more mentors, but we're always looking to support more people as well. That is our biggest problem, is not enough people know about us because what in the world is an Imerman, right? So Imerman is Jonny Imerman, our founder's last name.

He was a testicular cancer fighter at age 26, and he didn't know what to expect, although he had friends and families surrounding him all the time. And they all told him, "Hey, it's going to be okay. You'll get through this. You got this man," that's great to have. But it's kind of like if somebody says, "Yeah, go to that restaurant. Order this food, wear this outfit. That's not expensive. This is how you get there." And you're like, "Oh my goodness, thanks for all this information and advice. When's the last time you were at that restaurant?" And they're like, "Uh, never." It's not as helpful unless they've truly been there.

So how does this support start? Well, it's super easy. You just go to our website, which is just imermanangels.org, and you can go ahead and register there. We actually schedule calls for you through that website, or you can actually just call our phone number too, which is listed on the bottom of the screen. Either way, you will go ahead and get an assessment from one of our amazing cancer support specialists where they'll figure out your needs and prioritize those and figure out who we can match you with, that's going to be your best mentor. It's so unique because it's very different than a support group. You see, when you go to a support group... I'm not saying it's bad, it's good. But when you go to a support group, it's different. You have multitude of feedback, you have different ages, different experiences, and again, it could be so beneficial.

But when you have a peer, it is your person. It is your person that is around your same age that had the same number of children, that were the same age when you got diagnosed, could be the same cancer type, could have had the same treatment. You see, we dive down deep to get people matched to their exact person, their peer. 97% of the people that do get through our program, they actually report that they would recommend our service to other people going through this. And I always say, "We wouldn't recommend a bad restaurant." Right?

So here are some of the peer-to-peer organizations... Sorry, the peer-to-peer partners that we have. So what that looks like is these organizations allow us to do their peer-to-peer matches. So instead of recreating the wheel, they just go ahead and say, "Hey Imerman, you go ahead and make these matches for us." So, we are working together and really trying to build a community where no one feels alone. These are some of the additional resources that you can definitely find on our website. One that is most downloaded is the Grief Toolkit. So, anybody going through this experience, not just somebody that's lost a loved one but has lost something which oftentimes comes with this diagnosis, can use this Grief Toolkit to help them get through this.

Additionally, I would say that the journal is also really beneficial. It helps you with some prompts and just different ways of thinking of things. So please feel free to just visit our website there under the resources. And that's really all I have today. But just again, encourage you all to just... If you're ever thinking to yourself, "God, I wish somebody could answer that one question," you can. Just register with us and we'll find you that person. Thank you all for your time and your ears, and I'm sending you all well wishes.

Aimee Sax:

Thank you so much, Jackie. I've been referring to Imerman Angels for all eight years that I've been working at Sharsheret, and I love hearing more about what you all do, and I'm just so, so grateful. We do have that question from earlier that I wanted your take on. So, the person who shared that they haven't told their elderly parents, I hear this a lot as a Sharsheret social worker, that people have a lot of trouble breaking it to elderly parents. So, what are your tips for that or any thoughts you might have?

Jackie Herigodt:

It's interesting, because when you asked that question earlier and also Kelsey's information, I feel that a lot of the tips are similar. You know connecting with peers is obviously one of the first things I would say is connect and find out how they told their parents. So, you can get inside tips and tricks of what works and what doesn't. So, you can actually get connected to a few different people, but really about true and honest information, being as transparent as possible and just recognizing who you're speaking with and what level. You know your parents best probably, so you would know how to address the conversation, whether you are the family that sits down at the table every time and discuss conversations. In my family, we do have those sit downs. And before we do that, I will typically say like, "Listen, I have something that I need to discuss with you and you may not like it." I mean, that's the truth, right?

So being as open and honest as possible and just reading the room a bit and figuring out where are they at, at this time to give them the information. But from experience working in the organization, as long as I have had this experience. I would say that I have heard over and over again that caregivers that have not had the conversation about cancer, they feel very, I would say, challenged with the relation moving forward if they find out a different way that the person has had cancer. So, I would just say just be open, honest and take it slow. There's no rush into diving into the conversation but break it in there slowly if that's who you're dealing with.

Aimee Sax:

I so appreciate what you said about... You know, think about the relationship and how you deal with these things in your family. I always tell people family dynamics don't change when cancer comes in, they often get even more entrenched. So in my family, we had the sitting room, we only really used either when guests came over or when we had to have a serious chat. So, I kind of hated that room growing up because I always knew some bad news was coming if we went into that room to sit down.

So, I totally agree. Calling upon what you know about your family, whether it's children or other family members or other loved ones and fitting it into that framework I think is so important. Thank you. And I also know that sometimes when somebody comes to me with a question like this, I refer them to Imerman Angels because your Mentor Angels are so fantastic. And it's one of the only programs out there like it where caregivers can get matched up the resource... I mean with a peer mentor. So often when I'm talking to the parent of somebody going through cancer, I refer them to Imerman Angels because they can get matched with another parent whose child has gone through cancer and it's so, so beneficial. So, thank you so much, Jackie.

We're really just so lucky to have long-standing partnerships with both of these fantastic organizations. I know that I and the rest of our team of social workers refer to both of these organizations every single day. So, we're just really grateful to the support that both of you give to our community. So for those of you who might be joining from those two organizations and don't know about Sharsheret. I am going to share my screen to tell you just a little bit more about what Sharsheret can offer. So, forgive me one second.

Okay. So similar to Imerman Angels, we do have a peer support network. We really match people as specifically as possible to the issue they want to discuss. And sometimes you want one peer supporter from us and one peer supporter from them, that's okay. But we also do have our Family Focus program, which is really geared towards the needs of caregivers.

We use the term caregiver very loosely, so anybody who cares about you is going through this with you, we have a packet of materials with some gifts that we send to them. We also have our Facebook group, which is another really great way to get peer support from other caregivers who are going through it. We also have Facebook groups for people who are going through cancer or hereditary risk. And then we have our Busy Box, which I mentioned earlier, has a storybook that explains cancer at child's level, and we have different versions of that. So, we have the typical, you know, just a book about cancer. We also have a book about prophylactic surgery for somebody who might be doing that. And we also have a book, like I mentioned earlier, that is really geared towards those with special needs. Each Busy Box is packed with toys based on each child's ages and interests and also parenting resources for the parents.

And that is really up to age 12 because we know after that they kind of stopped playing with toys. So then for teens we do have our team packet. And also, for teens we have... Sharsheret's offering a film called My Second Backpack, how to best support your friends in meaningful ways, which was developed in accordance with the vision of Sherry Helfand Wiener. To help teenagers learn how they can help friends who are facing difficult situations. So sometimes we do this one-on-one, we share it with somebody who's currently going through cancer. Sometimes we help arrange a program like this at a school. So either is possible. Sharsheret approaches this topic using the lenses of breast and ovarian cancer. But the strategies explored in the film really work effectively for peers whose lives are affected by other cancers or other issues as well. The film is not intended to be viewed on its own, rather it's intended to serve as a prompt for discussion with an adult.

We recommend adults view the film at least once prior to watching it together with the teens. The discussion guide highlights five key concepts raised in and by the film. And depending, how the discussion goes, you'll choose which topics to really hit on. So, if you're interested in any of these programs, you can contact our clinical team to learn more. There'll be information in the chat for that. Also, for young adults ages 18 to 25, we have Sharsheret's Young ADult Caring Corner, which is here to help you understand your loved one's diagnosis. How you can help even from afar, we have a lot of young adults who maybe are away at college when their loved one is going through cancer. So how to take care of yourself while still caring for them. Our YAD Buddy System matches young adults ages 18 to 25 with someone who has also experienced a loved one's diagnosis of breast or ovarian cancer around the same age.

And just like our peer support program, we often hear that the act of being a supportive buddy can be just as, if not more powerful than getting the support. So if you have a young adult in your family that would like to get or give support in this way, please consider connecting them through the link in the chat. And a big thank you to Joy and Michael Goldsmith for their sponsorship and leadership in helping us create this program. Then our Embrace program is all of the above and more, but really specifically geared towards people with a metastatic diagnosis, as was mentioned earlier in the chat. Because we know once cancer becomes a chronic issue, then the needs change, so our resources and our support that we offer does as well. And then we also have different resources for kids who are thinking about community service projects to give back.

So most of these are often done in the Sharsheret world around a Bar, Bat Mitzvah, since most young adults weave in [foreign language 00:54:17] or community service component into their celebrations. But I've worked with many kids who plan, whether it's a Valentine's Day bake sale or bring Sharsheret to their school, maybe for my Second Backpack or another event, maybe to pack care kits for local chemo centers or even a lacrosse tournament. Whatever they'd like to do that's in line with their specific interests, we can make into a Sharsheret program and give them Sharsheret materials to share with people, giveaways, things like that. And through these projects, kids who have been personally affected by cancer in their families have the opportunity to take part in the Jewish concept of [foreign language 00:54:56] or giving to others with love and kindness, which can be so healing for them. But like I said, if they don't identify as Jewish, we are here for absolutely everybody regardless of background, and they can get in touch.

And then here's some of our other resources that maybe are not focused on children and caregivers but are still really worth mentioning. Our Best Face Forward kit comes with makeups and lotions. Everything's paraben and phthalates free, and we'd love to send that to anybody going through the cosmetic side effects of treatment. Our Thriving Again Survivorship kit comes with a binder that helps you keep your health records organized. It comes with a cookbook and the exercise bands to help you feel at your healthiest. We do have a lot of genetic support and resources. We have two genetic counselors who are fantastic. I learn so much from them every time. And we do have limited and focused financial assistance for scalp cooling, wigs and tattooing. So thank you so much to our partners, to Kelsey and Jackie. I know I learned so much from everything you both shared and I'm sure everyone else did watching as well.

We absolutely recommend that you follow our partners, Pickles Group and Imerman Angels on social media and get on their listservs to learn more about the things they offer. I also want to thank our sponsors GSK, Daiichi Sankyo and the Cooperative Agreement DP 19-1906 from the Centers for Disease Control and Prevention for their generous support. Please take a moment to fill out our brief evaluation survey that's linked in the chat box now. Evaluations really do inform our future programming, so we really appreciate you taking just a couple minutes to fill that out. Please never forget that our social workers and genetic counselors are here for you and your loved ones. Sharsheret provides emotional support, mental health counseling, and other programs designed to help navigate you through the cancer experience. And everything we do is free, completely private, one-on-one, and our number 866-474-2774 is available to everyone. And you can email us at clinicalstaff@sharsheret.org to get in contact with a social worker.

You can also email me at asax@sharsheret.org. Just let me know where you're located so I can make sure to make the right introduction for you. I do want to share an exciting webinar that we have planned soon on January 25th, Music and Movement. The link to register is in the chat. Everybody who joins those loves them. They are so much fun and it's just a nice way, even if you don't feel like getting up out of your chair, just feeling the vibes is great too. So please join us for that and check out our website regularly to see what other topics are coming up. A link for that is in the chat as well. And you can also access the recordings and transcripts for all of our past webinars. Soon this one will be up on the website as well. And the link for that is in the chat. So from all of us at Sharsheret, Pickles Group and Imerman Angels, thank you so much for joining us today. We wish you all a wonderful holiday season.